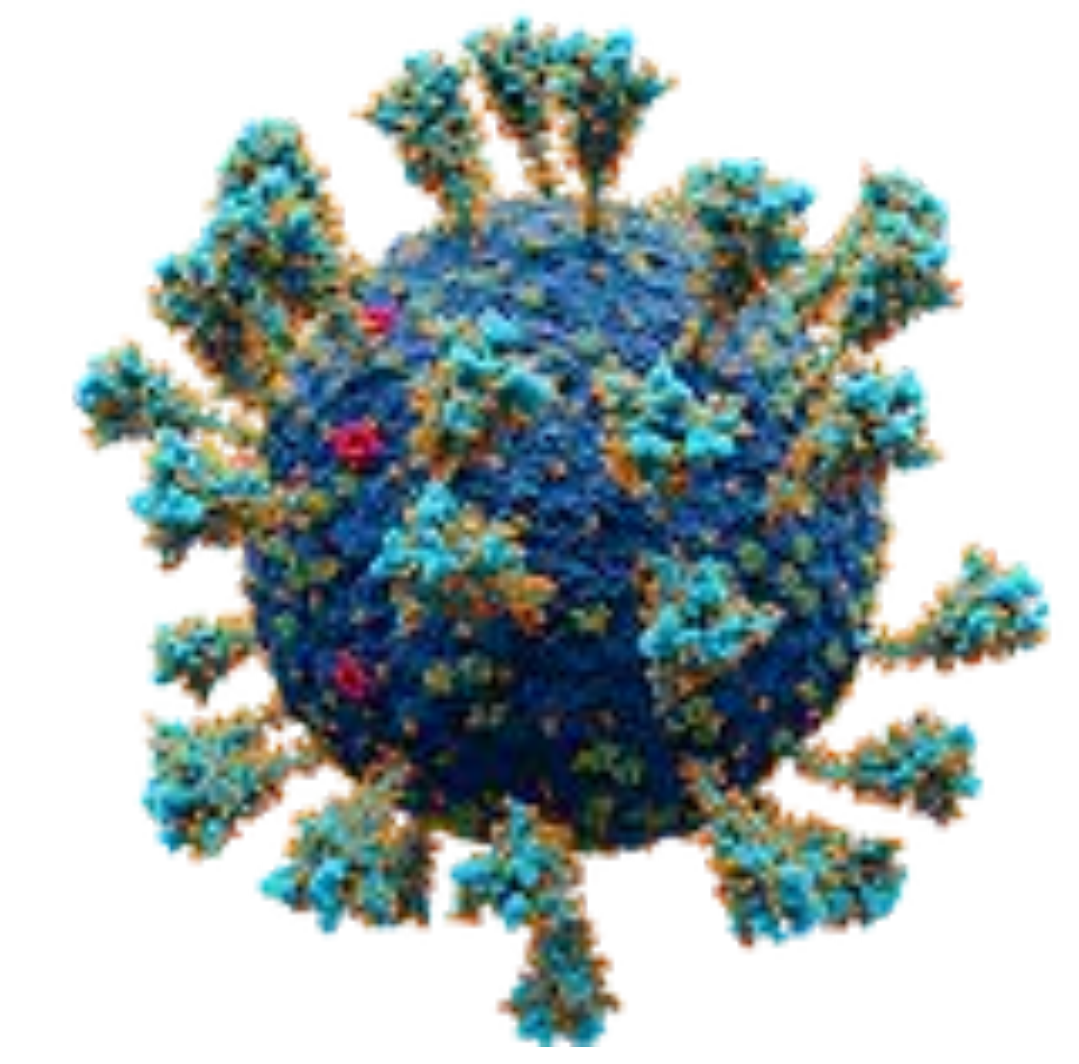


Equitable Treatment for Long COVID Patients in Rural States: Recommendations from a Sociologist/Sufferer/Survivor

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The Issue

When seeking medical treatment, all Long COVID patients begin the process at a disadvantage for they bear the stigma of a condition that they know is enshrouded in misunderstanding, disinformation, and political baggage. Add to this the unique challenges of seeking treatment in a rural state like Maine and the difficulties increase exponentially.

Methodology

Drawing from my experience as a 4+ year survivor/sufferer of Long COVID in Maine, by using autoethnographic methods, I lay out the challenges faced by Long COVID patients in rural, medically underserved, socioeconomically disadvantaged states and suggest policy and other changes that could promote greater health equity.

Challenges

- Finding primary care providers (PCPs) who are accepting new patients
- Finding PCPs who are up-to-date on education about Long COVID and able to competently diagnose, treat, and refer patients
 - It took me 1.5 years to receive a correct diagnosis and ultimately receive proper referrals
- Accessing care that does not require extensive travel
 - I travel to Boston regularly for care at Beth Israel's Long COVID Survivorship Program; this is expensive, time-intensive, and requires assistance because I am unable to drive
- Facing a likely forced reduction in work hours and possible job loss
- Health care/treatment costs that can increase exponentially
- Difficulty applying for and receiving SSDI and other benefits that Long COVID patients are entitled to receive
- Difficulty applying for and receiving ADA accommodations that Long COVID patients are entitled to receive
- Bearing the burden of having to regularly educate medical staff about one's condition
 - Even today, I encounter medical staff in the Bangor area who claim to have never heard of Long COVID or who claim to believe that the condition is "in patient's minds"
- Maine's only Long COVID clinic closed by MaineHealth in January 2023
- Almost no information is provided by the Maine CDC online for patients about how or where to get help. As of October 2024, Maine CDC's website is limited to the following information about Long COVID:

Long COVID Resources

What resources can I find online about Long COVID?

- US CDC: [Long COVID or Post-COVID Conditions](#)
- US CDC: [Caring for People with Post-COVID Conditions](#)

Where should I go for clinical care? Should I go to a Long COVID specialist?

- If you experience Long COVID symptoms, contact your primary care provider. They will help you create a plan for care. If you have ongoing symptoms that need special testing, your primary care provider might refer you to a specialist. They may refer you to a Post COVID Care Center if your symptoms need extra management.

Suggestions

- TRUST PATIENTS. BELIEVE PATIENTS. LISTEN TO PATIENTS.
- Increase telehealth capabilities throughout the state
- Eliminate Medicaid, Medicare, and private insurance restrictions on telehealth appointments
- Allow and facilitate cross-state telehealth services
- Increase and enhance education offered to rural health care providers
- Educate and assist employers in developing policies that support the recovery and continuing employment of employees suffering from Long COVID
- Revive at least one Long COVID center/facility in the state with strong remote access available to all Maine residents
 - Center should provide referral services to patients, help patients and caregivers connect with other patients and caregivers across the state, assist with SSDI applications, assist with requesting ADA accommodations, serve as a clearinghouse of information about emerging research findings, assist with enrolling in clinical studies, and provide additional services TBD
- Connect patients with one another via facilitated group sessions (via Zoom or other remote means)
- Connect caretakers with one another via facilitated group sessions (via Zoom or other remote means)
- Improve information provided by the state CDC online
- Involve patients in the process! We are the best advocates for ourselves. We know what we need.

Is this an issue you care about? Let's collaborate!

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